ChildAIDS

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NEWSLETTER OF THE NATIONAL FORUM ON AIDS AND CHILDREN

16 consent campaign continues

Organisations concerned with young people and HIV are to continue their support for the campaign to lower the age of consent for gay men to 16, after MPs narrowly voted against equality in February.

The Health Education Authority, Gay Men Fighting AIDS, and the British Medical Association are among those arguing for an equal age of consent on health as well as civil rights grounds. Dr Sandy Macara of the BMA has said that it is important to remove "the barrier that young men may perceive in seeking from doctors and others advice about their health and medical treatment".

The Terrence Higgins Trust argue that "the equalisation of the age of consent will significantly improve the effectiveness of AIDS campaigns targeted at young people and young gay and bisexual men in particular". At present, agencies giving advice about safer sex to young gay men run the risk of being accused of encouraging illegal behaviour.

In the UK there have been at least 177 reports of sexually acquired HIV in gay men under the age of 20, while many of those diagnosed between 20 and 24 were probably infected during adolescence. According to Hazel Yabsley, the coordinator of Positive Youth (a group of young people living with HIV): "Many of the young people feel that had they received appropriate sex education they would not be HIV positive today". Young gay men with HIV have to face "societal attitudes and legislation around their sexuality which makes them feel much less than equally valued, respected and worthy citizens".

The National Children's Bureau, Save the Children, British Youth Council, and other children's organisations have also voiced their support for an equal age of consent.

Young supporters of Stonewall (the organisation coordinating the consent campaign) have set up a new group for lesbians and gay men aged 16 - 25. YEARN (Youth Equality and Rights Network) is run by young people for young people. As well as continuing with the age of consent campaign, YEARN will pass on health information. As one founder member put it "If young lesbians and gay men are denied proper safer sex advice and a chance to communicate with one another because of our stupid laws, then we will have to do the job ourselves".

YEARN, c/o Stonewall, 2 Greycoat Place, London SW1P 1SB (tel. 071 222 9007).

Contents include: Forum news, HIV statistics, schools, working with young people, new publications, conferences and courses, Scottish news, plus four page supplement on: "Research in progress on children and HIV in the UK".

AZT Trial

Preliminary results of a joint US/ French study suggest that zidovudine (AZT) may reduce by up to two thirds the risk of transmitting HIV from infected pregnant women to their babies.

AIDS Clinical Trial Group (ACTG) study 076 began in April 1991. Women in the trial received either AZT or a placebo during pregnancy and labour, and for six weeks after birth infants received the same treatment as their mothers (i.e. AZT or placebo). By December 20 1993, 421 babies had been born of whom 364 had been accurately tested for HIV. Of these 364, 53 had HIV, 13 of them born to mothers receiving AZT, and 40 to mothers on placebo. The transmission rate was 8.3% when both mothers and babies received AZT, compared with 25.5% amongst those receiving a placebo.

Following an interim review of the trial by an independent Data and Safety Monitoring Board, enrolment to ACTG 076 trial has been stopped, and all pregnant women still on the trial are being offered AZT (including those who would have been given a placebo).

Dr Marie-Louise Newell of the Institute of Child Health in London said that "these results are of considerable interest as they suggest that it is possible to reduce the risk of vertical transmission. However, they also pose new questions and do not shed light on the issue of the timing of transmission. Also, the long term effects of AZT on these infants are unknown".

No recommendations about treatment are expected at least until a full report of the study has been published and analysed. Researchers will continue to monitor the health, growth and development of infants born in the study.

NATIONAL FORUM ON AIDS AND CHILDREN

The National Forum on AIDS and Children brings together organisations concerned with children infected or affected by HIV, from both the voluntary and statutory sectors.

The Forum aims to promote the interests and welfare of children and young people in relation to HIV/AIDS issues by:

- *promoting an effective voice for children.*
- *providing a national resource and data-base.*
- *disseminating information about good practice.*
- *promoting research and training.*
- *identifying un-met needs and promoting service development.*
- *campaigning and lobbying, representing members' views to government, media and outside bodies.*

ChildAIDS, the newsletter of the National Forum on AIDS and Children, is published quarterly. Views expressed in the newsletter do not necessarily reflect those of the Forum as a whole.

Contributions of articles, materials for review, or any relevant information, are welcomed and should be sent to the editor, **Neil Orr**, at the following address.

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Telephone: 071 278 9441. Fax: 071 278 9512.

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JOIN THE FORUM

The National Forum on AIDS and Children has now been established as a membership organisation. Membership is open to all agencies concerned with children and HIV/AIDS who agree with the Forum's campaigning aims (see below).

Members will be able to work together with a range of organisations from health, social services, education, and the voluntary sector to promote the interests of children infected or affected by HIV/AIDS. Other benefits of membership include:

- one year's subscription to Child-AIDS newsletter (four issues), the only regular UK-wide publication on children and HIV.
- Forum meetings: In the last year meetings have covered such topics as children's rights, informing children about their HIV status, and working with older children.
- mail outs, including details and minutes of meetings, Forum information sheets, draft documents etc.
- access to the Forum's information service: the Forum is developing a database of services and resources. Forum members can receive photocopies of articles at a reduced rate.

To help cover some of the costs of printing, postage, and other expenses, there is a small annual membership fee. The rates are as follows:

- statutory organisations and national voluntary organisations: £30.
- small voluntary organisations: £15.
- individuals may become associate members for £15 per year.
- libraries and others who wish to receive the newsletter without joining the Forum may take out a year's subscription (four issues for £15).

*Please make cheques payable to the **National Forum on AIDS and Children**.*

CAMPAIGNING AIMS:

1. Promote an effective voice for children and young people who are infected or affected by HIV.
2. Increase knowledge and understanding about the impact of HIV on children and families.
3. Promote the rights of children and combat prejudice and discrimination.
4. Promote the adoption of HIV policies which are child-centred and enhance good practice.
5. Promote the development of services to meet emerging and unmet needs.
6. Promote good practice which enhances the quality of life for all children who are infected or affected by HIV.
7. Promote training and staff development for professional staff and volunteers involved in planning and providing services.
8. Promote research which identifies and explores the impact of HIV on children and families.
9. Improve allocation of resources to meet rising demands.

All campaigning will be carried out within the Charity Commissions's restrictions on political activity.

RESPITE CARE MEETING

The next meeting of the Forum is on "Respite care for children and families affected by HIV", and will be held at 2:00 pm on Tuesday May 24th in London (venue to be confirmed). Speakers will include Dee Donnelly (East London Childcare Initiative) and Juliet Ramage (Westminster Social Services), who will be talking about developing new HIV services, and Christine Lenahan (Barnardo's Families Together) who will be providing an overview of good practice in respite care based on her experience with children with special needs.

NEW LONDON SERVICES

A number of new services for families affected by HIV are currently being developed in London. The East London Childcare Initiative has been set up to assist the four participating boroughs (Hackney, Tower Hamlets, Newham and Waltham Forest) to recruit and train a range of carers to meet the needs of children and families. Dee Donnelly has recently taken up the post of Project Manager of ELCI.

It is proposed to focus recruitment on population groups that are underrepresented in the existing pool of childminders, and to recruit carers able to be flexible in the sense that they may work in the user's home or their own home, depending on needs. For example, offering overnight respite care when necessary.

In Westminster, Juliet Ramage is coordinating a new respite care scheme for children and families affected by HIV, while in Lambeth a respite care scheme for children with special needs is being developed by the childminding department. This will initially focus on children affected/infected by HIV/AIDS aged up to eight-years-old.

- *Dee Donnelly, East London Child Care Initiative, 100 Shepherdess Walk, London N1 7JN 1HR (tel. 071 250 1390).*
- *Juliet Ramage, Respite Care Coordinator, Family Link Scheme, City of Westminster, 155 Westbourne Terrace, London W2 6JX (tel. 071 798 1452).*
- *Linda Harrington, Children and Families HIV Development Social Worker, St Thomas Hospital, Lambeth Palace Road, London SE1 7EH (tel. 071 928 0351).*

SURREY GUIDELINES

Surrey Social Services Department have developed comprehensive operational guidelines to provide staff with a framework for good practice when working in the field of children and HIV. The guidelines start from the principle that "Children affected by HIV as well as HIV positive children are defined as children in need and therefore are entitled to our services". Procedures are detailed for confidentiality, testing, referrals and case management, day care, fostering, adoption, residential care and child protection.

Ruth Smallacombe, Development manager (HIV), Surrey Social Services Department, AC Court, High Street, Thames Ditton, Surrey KT7 OQA (tel. 081 541 8703).

MERSEYSIDE

Fran Doran has been appointed to work with Barnardo's in conjunction with Merseyside Health to look at what services are available for children affected/infected by HIV locally, and to make recommendations for the future development of services.

Barnardo's, Merseyside House, 9 South John Street, Liverpool L1 8BN (tel. 051 708 7848).

NEW WARD AT GREAT ORMOND STREET

Children with HIV at Great Ormond Street hospital are now being cared for in the Infectious Diseases Unit in the new Variety Club Building. The unit is decorated in a child-friendly style, with walls, floors and curtains reflecting a safari theme (the unit is in Giraffe ward). Most children have their own rooms, with a spare bed so that a parent can stay overnight, and a bathroom. A state-of-the-art air filtration system ensures that the air within the rooms and on the ward is constantly changed and cleaned, minimising the risks of children with compromised immune systems picking up infections. There is a specially designated play area on the ward, with a play worker.

Further information from: Candy Duggan, Room 120, Institute of Child Health, 30 Guilford Street, London WC1N 1EH.

HIV STATISTICS

By January 31st 1994, there had been 594 reports of children being born to HIV positive mothers in the UK (352 in the Thames Regions, 99 in the rest of England, Wales, and N. Ireland, and 143 in Scotland). Of these, 224 are known to be infected, 179 are uninfected, and 191 are of indeterminate status.

In addition by 31st October 1993, 283 children (aged 14 or under) in the UK have become infected with HIV via infected blood or blood products, and nine have become infected in undetermined ways. 215 of these are now aged 15 or over, or were at the time of death. Out of a total of 516 confirmed cases of HIV in children aged 14 or under, there have been 99 deaths.

National Study of HIV in Pregnancy, March 1994; *Public Health Laboratory Service*, 31 January 1994.

In the USA, by October 1993 there had been 4906 cases of AIDS in children under 13 years, out of a total of 339,250 cases. (source: Centre for Disease Control and Prevention).

CHILD TO CHILD TRANSMISSION

A case of HIV being transmitted from one child to another in the home has been documented in the US. Although the mode of transmission was not definitively established it seems likely that a child with open skin lesions was infected through exposure to the blood of the other child, who had frequent nose bleeds and gum bleeding.

As the New England Journal of Medicine points out, such cases are extremely rare: "17 studies of persons in the US and Europe who had contact in the household, not involving sex or shared needles, with HIV infected persons, found no infections among more than 1100 people, including more than 300 children". Nevertheless "precautions are warranted to prevent contact with blood in households and similar settings".

Fitzgibbon, JE et al (1993), Transmission from one child to another of HIV type 1 with a zidovudine-resistance mutation, *New England Journal of Medicine*, 1835-41, 16 December, and editorial, 1883-85.

SCHOOLS AND HIV

Sex Education Circular

The Department for Education circular **Education Act 1993: Sex education in schools** is due to be issued in April 1994. According to the Department, the circular will "explain the new legislative framework for sex education" and "give advice on the appropriate content, and on the development and implementation of policies and programmes, of sex education set within a clear moral framework" (the circular will apply in England and Wales, but not in Scotland).

The draft of the document issued for consultation in December 1993 made it clear that in secondary schools sex education "must include, at a point appropriate to the age and maturity of the pupils, education about HIV and AIDS". A National Forum on AIDS and Children response urged a recognition in the circular (lacking in the draft) that those providing education about HIV need to be sensitive to the needs and concerns of children infected or affected by HIV, whether or not they are individually known to the school or teacher. Much HIV education focuses solely on prevention, implicitly assuming that HIV is not already an issue for some children.

The Forum also expressed concern about the sections of the draft dealing with advice to individual pupils. The draft suggested that it is inappropriate and in some circumstances criminal for teachers to provide contraceptive advice to an individual pupil under 16 without parental consent. Furthermore it stated that if a pupil discloses to a teacher that she or he "has embarked upon, or is contemplating, a course of conduct which is likely to place him or her at moral or physical risk or in breach of the law", the school should "ensure that the parents are made aware".

The Forum response pointed out that young people under the age of 16 may be at risk of HIV, or indeed already infected, as a result of sexual behaviour or injecting drug use. The provisions of the draft circular would be likely to discourage such young people from seeking advice in schools on these matters, and staff discouraged from providing such advice. The approach taken in the draft circular contrasts with that taken in the Department of Health's **Children and HIV: guidance for local authorities** (1992), which states that a young person under 16 who wants information kept confidential from parents should generally only be overruled if there is a risk of significant harm to the child if disclosure is not made.

A legal opinion by Alan Levy QC states that a teacher giving advice would be unlikely to be convicted for aiding and abetting unlawful sexual intercourse (Section 28 of the Sexual Offences Act, 1956) providing he or she honestly intends to act in the pupil's best interest and there is a bona fide exercise of professional judgement.

A recent survey* found that 84% of 13 to 15 year olds would find it helpful to talk to a teacher for advice about things like contraception, but that only 31% would do so if the teacher was likely to tell their parents what they said.

* *Young people's attitudes towards sex education, prepared by BMRB for the Family Planning Association, 29 March 1994.*

Europe

The recently established European Forum on HIV/AIDS, Children and Families is hoping to undertake a collaborative cross-country study addressing the needs of children, parents, and teachers in relation to HIV in the school community.

The focus would be on collating and evaluating information on school policies and practice, and on staff training, in the five participating countries: France, Italy, Spain, Portugal, and the UK.

Following a programme of questionnaires, school visits, and interviews, guidance on good practice on HIV and schooling would be published.

A meeting is to be held in Paris in May to develop a more detailed proposal.

Details from: Naomi Honigsbaum, European Forum on HIV/AIDS Children and Families, National Children's Bureau, 8 Wakley Street, London EC1V 7QE.

Newham Education Policy

The London Borough of Newham's Education Department have launched a new HIV/AIDS Policy Statement. As well as dealing with education about HIV, the statement recognises the needs of children in schools who are already living with HIV.

The stated aims include:

- "To ensure students' continued access to their full educational entitlement, regardless of their actual or imputed HIV status".
- "To protect students from discrimination on the grounds of actual or imputed HIV status".

The policy makes it clear that "there is no reason why any pupil or students should be excluded from any Educational Department establishment if they have HIV". In relation to confidentiality, it is stated that "School staff cannot be expected to be informed of a child's HIV status", and that staff must ensure that "disclosure only takes place on the terms agreed (in writing if requested) with the child and the family".

To ensure that the policy is implemented, each school is expected to a appoint a HIV/AIDS Co-ordinator, who will receive appropriate training.

Further details from: David Lister and Julia Bird, Newham Education Department HIV/AIDS Liaison Officers, Broadway House, 322 High Street, London E15 1AJ (tel. 081 555 5552).

▣ Lothian Regional Council HIV/AIDS Education Team are currently revising their guidelines on children with HIV. They would welcome copies of other education authorities' guidelines to inform their thinking.

Contact: John H Young, Lothian Regional Council HIV/AIDS Education Team, Westwood House, 498 Gorgie Road, Edinburgh EH11 3AF (tel. 031 469 5855).

Research in progress on children and HIV in the UK

This information sheet summarises research in progress (or planned) relevant to children infected or affected by HIV in the UK.

It includes both clinical research and work on the psychological and social impact of HIV (it does not attempt to cover HIV prevention and education).

It is hoped to regularly update this information, so reports of any other relevant research would be welcome.

❑ *THE IMPACT OF HIV ON FAMILIES: IMPLICATIONS FOR HEALTH CARE SERVICES.*

There are estimated to be 500 children living with HIV positive parents in Edinburgh. Literature is extensive and services well advanced in terms of HIV positive children, however little attention had previously been given to the impact on family life where children are HIV negative.

The aims of this study are:

- to document the effect of HIV on family structures and care arrangements in the family. To define the family.
- to examine parents perceptions of services available and future needs.

The study commenced in October 1992 and is funded for two years by a Research Training Fellowship awarded by the Scottish Home and Health Department. Twenty-five families have been recruited. Parents and other family members who are currently (or as circumstances change will be) involved in child care are interviewed at regular intervals. The data is then analyzed qualitatively. A further statistical analysis of the number of affected children in Lothian is also being carried out.

Expected date of publication is end of 1994.

For further information contact: Hugh Masters, Dept. of Public Health Sciences, University of Edinburgh, Medical School, Teviot Place, Edinburgh EH8 9AG (tel. 031 650 3235, fax 031 667 6129).

❑ *CHILDREN AND YOUNG PEOPLE INDIRECTLY AFFECTED BY HIV/AIDS: THE EXTENT AND THE NATURE OF THE PROBLEM.*

The number of children in the UK known to be HIV+ or to have AIDS is relatively small, while the number of children indirectly affected because of HIV infection of parent(s) or carer(s) is believed to be much higher. There are no official statistics on the parental status of adults who test HIV+, thus planners and social care providers lack basic information on a vulnerable group of children and young people who may need extensive support and possibly full time care during the illness and following the death of their parents.

With a view to providing evidence of the scale of need, Barnardo's intends to commission research which will explore the numbers and circumstances of dependent children and young people whose parent(s) or carer(s) have HIV/AIDS. The study is expected:

- to give an informed estimate of the extent of the problem of indirectly affected children and young people.
- to establish the circumstances and range of needs through interviews with a number of parents and where possible, indirectly affected young people.

Barnardo's have invited a number of agencies to tender to carry out this research. Further information from: Dr Helen Roberts (Co-ordinator, Research and Development), Barnardo's, Tanners Lane, Barkingside, Ilford, Essex IG6 1QG (tel. 081 550 8822).

❑ *INFORMATION MATERIAL FOR CHILDREN AND YOUNG PEOPLE LIVING WITH HIV/AIDS.*

This project will investigate the need for information material directed at young children as well as young people living with HIV and AIDS. The initial phase is a needs assessment exercise, looking at the perceived needs of carers as well as service providers. The outcome of this should be the production of material suitable for children aged five to ten, as well as those aged ten to fifteen, which will help carers talk about HIV and AIDS to children and young people. Examples of materials already produced and/or comments on these would be welcome. Funded by the Hedley Trust.

Dr Jacqueline Mok and Dr William Cutting, Paediatric AIDS Resource Centre, 25 Hatton Place, Edinburgh, EH19 1UB (tel. 031 668 4407).

❑ *AN INVESTIGATION INTO THE RELATIONSHIP BETWEEN HIV AND THE DEVELOPMENT OF SPEECH AND LANGUAGE SKILLS IN CHILDREN.*

This study aims to look at the development of speech and language skills in children infected with HIV, comparing them with children presumed uninfected. The research is due to start shortly, pending approval by the local Ethics Committee.

Contact: Dr Jacqueline Mok, Regional Infectious Diseases Unit, City Hospital, Greenbank Drive, Edinburgh EH10 5SB.

❑ *THE IMPACT OF HIV ON FAMILIES.*

This study involves interviewing patients attending the Royal Free Hospital AIDS Centre with a view to determining (a) who they define as their family (b) to whom they have disclosed their diagnosis (c) reasons for non-disclosure (d) patterns of social support. Results are expected to be available later this year.

Dr Robert Bor, Centre for Counselling Psychology, City University, Northampton Square, London EC1V OHB (tel. 071 477 8523), with Dr Jonathan Elford (Royal Free School of Medicine).

❑ *HOSPITAL AND COMMUNITY SERVICES FOR FAMILIES AFFECTED BY HIV INFECTION AND AIDS.*

This study has two related aims. The overarching aim is to investigate which hospital and community services are used by families with HIV infected children treated at the NW Thames Paediatric HIV Unit, St Mary's Hospital, to estimate their costs, and to assess their effectiveness, efficiency and acceptability. To provide the context for making such assessments, a second aim of the study is to investigate and describe the impact on families of HIV infection in a child, including how the illness is managed within the family and how this influences and is influenced by the availability and use of professional services.

The design of the study involves both prospective and retrospective components. Families who are currently attending the NW Thames Paediatric HIV Unit will be followed for six months to assess their health status, their family functioning, their use of hospital and community services and their views on these services. The views of the providers of these services and the costs of the services will also be obtained. Similar data will be obtained retrospectively from hospital records for families who have attended the Unit in the past.

Contact: Dr Eddy Beck or Dr Mary Boulton, Academic Department of Public Health, St Mary's Hospital Medical School, Norfolk Place, London W2 1PG (tel. 071 723 1252).

❑ *PAEDIATRIC HIV/AIDS SERVICES AT AN INNER-LONDON TEACHING HOSPITAL.*

This study examines current issues in service provision to HIV infected children and their families at an inner-London teaching hospital. Ten parents have been interviewed about their use of hospital and community services, and their views on how these might be improved. They seem to very satisfied with the care provided by the paediatric HIV team, but have less confidence in GP and community services, preferring to use hospital services which they feel have more expertise. A report of this study has been accepted for publication in the journal AIDS Care, under the title "We just want to be a normal family".

Geraldine Barret and Christina Victor, Department of Public Health, Kensington & Chelsea and Westminster Commissioning Agency, Bay 8, 16 South Wharf Road, London W2 1PF.

❑ *PSYCHOLOGICAL FOLLOW UP OF CHILDREN INFECTED OR AFFECTED BY HIV.*

Developmental measure (including measures of language, cognitive and motor skills) together with ratings of behavioural and emotional adjustment are being collected on groups of children. All are from families being seen at St Mary's Hospital. The groups being followed include:

- children who have been tested as HIV positive.
- children whose HIV status is indeterminate (born to HIV positive mothers but too young for their own status to be clear).
- children who have been tested and are HIV negative.
- affected children, including siblings of children who are positive, and children living in families where one or both parents are infected.

Some family and environmental factors are also being collected. The major coping tasks facing these families and children are being identified. The incidence and nature of feeding and eating difficulties within the above groups is being studied in a joint project with the department of nutrition and dietetics.

Diane Melvin, St Mary's Hospital Paediatric HIV Team, 7th floor, QEQM wing, South Wharf Road, London W2 1NY (tel. 071 725 6349).

❑ Lorraine Sherr at St Mary's Hospital is researching some of the legal and ethical issues surrounding HIV infection and children.

❑ *AZT AND CHILDREN (PENTA 1 STUDY)/ AZT AND DDC (PENTA 3 STUDY).*

A number of UK paediatric centres are participating in these multi-centre European trials, organised under the auspices of the Paediatric European Network for Treatment in AIDS (PENTA).

The PENTA 1 trial is for children born with HIV with minimal or no symptoms. It aims to determine whether early treatment with AZT is more effective in delaying progression to AIDS than treatment which is started only when symptoms are present. It also aims to evaluate the toxicity of long term AZT treatment in children and to study the development of resistance to the drug.

AZT and ddC both belong to a class of drugs known as nucleoside analogues. The benefits of AZT in children are limited and are not maintained indefinitely, possibly because HIV strains resistant to AZT develop. It has been suggested that combinations of AZT and ddC might be more effective and less toxic than treatment with AZT alone. The PENTA 3 study aims to compare the combination of AZT plus ddC with monotherapy with AZT in children with symptomatic HIV infection who have never taken anti-HIV drugs before.

Further details from Jenny Bates / Linda Harper, MRC HIV Clinical Trials Centre, Dept. of Clinical Epidemiology, Royal Brompton National Heart and Lung hospital, Sydney Street, London SW3 6NP.

❑ *INVESTIGATION OF A T-CELL SUBPOPULATION.*

T-cells (T-lymphocytes) are white blood cells that play a crucial role in the functioning of the immune system. This project is investigating the role of a subpopulation of T-cells (CD45RO+CD8+) which is present in abnormally high proportions in children born with HIV. It is hoped that this will enable a greater understanding of vertically acquired HIV infection.

Dr Karin Froebel, Dept. of Medicine, HIV Immunology Unit, Lauritson Building, Royal Infirmary, Edinburgh, with Dr Jacqueline Mok, City Hospital.

❑ *RESEARCH AT THE HOSPITAL FOR SICK CHILDREN, GREAT ORMOND STREET.*

Research in progress includes:

❑ a study with a centre in Italy to look at how well children with HIV respond to vaccination with haemophilus and pneumococcal vaccines. These vaccines are recommended for all infected children because of the high incidence of bacterial infections, but as yet it is unclear how well children at different stages of the disease will respond to the vaccinations and therefore be protected against these infections.

❑ a study with Richard Tedder and the Virology Department at the Middlesex Hospital looking at development of resistance in children on AZT and also ways of measuring virus load in children's blood. Over the past few years the group has also been evaluating its PCR test, which is routinely used to make an early diagnosis in babies born to positive mothers at Great Ormond Street.

Further details from Dr. Diana Gibb (for address see "confidential unnamed surveillance..." below).

❑ *NATIONAL STUDY OF HIV IN PREGNANCY.*

Data is collected from obstetricians on pregnancies in HIV infected women in the UK and Ireland, and the HIV status of the children born to them. The results are published in a quarterly newsletter, funded by AVERT. This study is closely linked to the British Paediatric Surveillance Unit scheme reported below.

Contact: Dr. Clare Davidson, National Study of HIV in Pregnancy, Royal College of Obstetricians and Gynaecologists, 27 Sussex Place, Regent's Park, London NW4 RG1 (tel. 071 849 8686).

❑ *LIP AND BACTERIAL INFECTIONS.*

Lymphocytic interstitial pneumonitis (LIP) is a lung disease that affects children infected with HIV, often presenting in the second year of life. Severe bacterial infections including pneumonia are recognised as being more common in infected children; children with LIP however seemed to have even more chest infections than those without LIP.

The London collaborative paediatric HIV group therefore set up a clinical study to look at the relationship between LIP and chest infections. The case notes of 92 vertically acquired HIV infected children were reviewed from 3 London centres (Great Ormond Street, St Mary's and St George's Hospitals). Ten children had PCP and were excluded from the analysis. A chronic cough and persistent chest signs were common in the whole group, but both were significantly more common in the children with LIP.

A total of 49 admissions with acute lower respiratory tract infections had occurred. However admissions were seen more commonly in those children with LIP, some children having more than five admissions with pneumonia. The total group have required over 500 admission days so far in the three hospitals.

It is clear that many children are having serious problems with recurrent episodes of pneumonia, and most of these children have LIP. The cause of LIP is as yet unknown. There is limited data suggesting that LIP may represent an over activation of the immune system. The research group based at St George's is now concentrating on trying to improve the methods of diagnosing LIP, and trying to confirm the activation of the immune system. It is particularly important to identify whether this is a response to the HIV virus, or some other triggering factor, possibly a different viral infection.

Data from this study has been submitted for presentation to the British Paediatric Association. Further details from Dr Mike Sharland (Senior Registrar in Paediatric Infectious Diseases), St George's Hospital, Blackshaw Road, London SW17 0QT (tel. 081 672 1255, ext. 55973).

Further reading...

- The British Paediatric Association's **Guidelines for the ethical conduct of medical research involving children** (1992) covers such issues as consent, and assessing potential benefits and harm.

BPA, 5 St. Andrew's Place, London NW1 4LB.

- The best general source on clinical trials is the **UK Directory of HIV/AIDS Treatments and Trials**, published by the National AIDS Manual. NAM also publish the regular newsletter **AIDS Treatment Update** (the Nov. 1993 issue included an 11 page section on treatment issues for children).

*Details from: **National AIDS Manual**, Unit 52, the Eurolink Centre, 49 Effra Road, London SW2 1BZ (tel. 071 737 1846).*

- For information about US clinical trials, see the **AmFAR AIDS/HIV Treatment Directory**, published three times a year by the American Foundation for AIDS Research, 733 Third Avenue (12th Floor), New York, NY 10017-3204, USA. A number of UK AIDS organisations have copies in their libraries, including the Terrence Higgins Trust.

- The **Medical Research Council AIDS Behavioural Forum Register of Research** (August 1993) includes a wide range of research projects looking at such areas as sexual behaviour, attitudes and health education in relation to HIV. Many of these projects focus on young people.

Details from: Kaye Wellings, MRC AIDS Behavioural Forum, Academic Department of Public Health, St Mary's Hospital Medical School, Norfolk Place, London W2 1PG.

This information sheet was edited by Neil Orr, April 1994; publication was assisted by a grant from The Mackintosh Foundation.

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❑ *CONFIDENTIAL UNNAMED SURVEILLANCE OF PAEDIATRIC HIV.*

Since 1989, paediatricians in the British Isles have reported all cases of HIV seropositive children with HIV through the active monthly reporting scheme at the British Paediatric Surveillance Unit. Data is collected on details of symptoms and treatment, with each report being followed up annually to monitor clinical progression, age at onset of AIDS, and age at death (see A.E. Ades et al, Vertically transmitted HIV infection in the British Isles, British Medical Journal, 15 May 1993, vol.306, p.1296-1299).

A study of Pneumocystis carinii pneumonia was recently carried out through the BPSU, finding that PCP caused 82% of AIDS-related infant deaths (see the article by D.M. Gibb et al in Archives of Disease in Childhood, March 1994, vol.70, p.241-244).

Dr D M Gibb, Epidemiology and Biostatistics Unit, Institute of Child Health, 30 Guilford Street, London WC1N 1EH.

❑ *EUROPEAN COLLABORATIVE STUDY.*

The European Collaborative Study was set up in late 1986 with the following objectives:

1. To estimate the rate of mother-to-child transmission.
2. To identify risk factors associated with increased transmission.
3. To elucidate the natural history of vertically acquired HIV infection.

At present over 20 European centres from eight countries are involved in this study, and more than 1500 mother-child pairs have been enrolled. The City Hospital, Edinburgh, is the only UK centre participating at present, although the Westminster-Chelsea centre in London has also joined the study recently.

The main findings to date are:
- the rate of mother-to-child (vertical) transmission is about 15%. Risk factors associated with increased transmission include advanced HIV disease in the mother, low CD4 counts or p24 antigenaemia (presence of a HIV protein in the blood) in the mother, possibly mode of delivery, and certainly breastfeeding.
- about 25% of infected children are diagnosed with AIDS in the first year of life, and 15% have died by age one year. By age five it is estimated that about 75% of infected children are still alive, often without serious HIV disease. This has obvious implications for health care and social provision planning.
- many children do live with one or both parents, although by the age of five about 40% are looked after by others (often grandparents).

The study hopes to shed further light on the risk factors for vertical transmission and markers of progression of disease in the children. In addition an interventionist arm will become part of the ECS. A protocol is currently being developed to evaluate interventions aiming to reduce vertical transmission.

Further details from Dr Marie-Louise Newell, European Collaborative Study, Institute of Child Health, 30 Guilford Street, London WC1N 1EH (tel. 071 829 8699).

❑ *EUROPEAN COHORT STUDY OF HIV IN HAEMOPHILIA.*

Ten haemophilia centres in northern Europe (including four in England) are pooling data on 202 haemophiliac children who were infected with HIV between 1979 and 1986, the age of infection ranging from 1 - 15 years. Data is being collected on clinical progression of HIV disease and treatment patterns. A report of this study was published in Archives of Disease in Childhood, vol. 68, p.521-524, 1993.

Contact: Dr. A. Aronstam, Basignstoke General Hospital, Basingstoke, Hants, RG24 9NA.

SCOTTISH HIV GUIDANCE

by Sarah Morton

In September 1993 , the Scottish Office published its long awaited **Children and HIV - Guidance for local authorities and voluntary organisations**. Although Scotland has been pioneering policy in this field, the Department of Health published their Guidance for England and Wales in advance of the Scottish document. After a consultation based on a separate Scottish document, the Scottish Office decided to publish a copy of the English Guidance, with amendments relating to Scottish Law, and the inclusion of voluntary organisations within the remit. Whilst it seems a good idea for there to be parallel policy for Scotland, it is questionable why this was not done at an earlier stage, and on document produced for the whole UK.

At a conference organised by Children in Scotland with support from the Scottish Office, at the end of October, people working with children from across Scotland gathered for the first time to consider the issues of HIV and the impact of the Guidance. Harriet Dempster, Assistant Chief Inspector of the Social Work Services Group stressed that "approaches to children with HIV should be set within a framework of the general principles of good child care practice. Children living with HIV should be seen as children first". Other speakers emphasised the issues for statutory and voluntary agencies. Gerry O'Hara, Principal Officer Child Care, Lothian Regional Council highlighted the tensions within the policy. For example the Guidance states that parents should give their permission before schools are informed, "but in reality there are parents who are dying who won't give this permission. Their children are distressed - and teachers don't know why. The easiest thing in the world is not to do anything about it".

The focus of the day was very much on how the guidance can be put to use by those working with children in all sectors. There was a general feeling that resources will need to be made available if the recommendations are to be carried out.

How can the Guidance be best put to use?

1. Ensure that your agency has enough copies, and that anyone likely to deal with children has access to a copy and know of its existence.

2. There are a range of training opportunities that can be pursued:

- training in basic hygiene procedures and HIV awareness should be given to all those who work with children.
- there are recommendations for further training for those working directly with children affected by HIV.
- those working with young people in care should have training on counselling around sexuality.
- all carers should also receive training on the impact of HIV on caring for all children.

3. Planning sections need to consider the implications for policy, and ensure that projects under their control are developing relevant policy and practice.

4. Individual projects need to consider their operations in relation to the Guidance, and how well developed their current policy and practice is.

Children in Scotland is currently pressing for funding for a user's guide to the Guidance. This would provide information for families about the level of service they can expect.

Copies of the Guidance are available from Social Work Services Group, Room 429, 43 Jeffrey Street, Edinburgh EH1 1DN.

A Children in Scotland Factsheet summarising the Guidance is available from our offices at Princes House, 5 Shandwick Place, Edinburgh EH2 4RG (tel. 031 228 8484). Price: single copies free with a SAE; multiple copies, 25p each or ten for £1.

TAYSIDE FORUM ON CHILDREN AND HIV

At a meeting on 7th December 1993 of a variety of agencies in the statutory and voluntary sectors in Dundee, it was agreed to set up a Tayside Forum on Children and HIV. The aim of the forum will be to enable people working in this area to get together to discuss issues, meet others in the field, identify gaps in service provision, and to press for better services. A Steering Group has been established, with Children in Scotland providing a focal point to the Forum.

• Children in Scotland and the Paediatric AIDS Resource Centre are producing a regular current awareness bulletin. The 2nd issue (March 1994) includes a review of breastfeeding and HIV by Dr William Cutting (available from Children in Scotland, address above).

PRACTICE STANDARDS WORKING DAY

6th December 1993, Edinburgh.

The National Forum on AIDS and Children Working Group on Practice Standards brought the draft of their document to Scotland by invitation from Children in Scotland and BBC Children in Need. A range of agencies involved in service delivery to adults were invited to consider the relevance of the document, which aims to sit alongside the Scottish Office and Department of Health Guidances, but doesn't presume a background knowledge of child care issues. The day focused closely on the document and allowed people to consider sections of it in small working groups. The overall feedback was that the document raised important and difficult issues, and that it is of interest to those who provide services as well as funding agencies.

WORKING WITH YOUNG PEOPLE

A National Forum on AIDS and Children meeting hosted by Derbyshire Social Services in October 1993 looked at the needs of older children and young people infected or affected by HIV. Hazel Yabsley of Positive Youth and Graham Sutterby from the Barnardo's Broad Street Project described their work in this area.

POSITIVE YOUTH!

Positive Youth is a self-help group for young people (aged 16 - 25) living with HIV and AIDS, based in London. It is mainly, though not exclusively, made up of young gay men. with a diverse range of circumstances: some are drug users or ex-drug users, some are involved in prostitution, some are homeless, some are living with their parents. Their needs include:

• peer support and friendship: living with HIV can be an isolating experience. Positive Youth provides not just emotional support, it also enables people to share practical experience (e.g. names of good GPs and dentists). There is a closed support group for young people with HIV, as well as a more open social group organising such events as ice skating and rock climbing.

• confidence building: young people may suffer from low self-esteem on being diagnosed. Some give up work or college, while others may just find it hard to make decisions. Positive Youth offers personal and skills development through training courses, as well as access to counselling.

• access to services and benefits: one to one advice and referral is available. An example of the sort of problems young people face might be being thrown out of the family home for being gay or HIV+, and having difficulty getting rehoused, particularly if they are asymptomatic.

• accurate information: Positive Youth is based at the Body Positive centre which has a good library and information service. The group is currently writing a booklet for other young people affected by HIV, based on their own experiences.

• somewhere to go during the day: the Body Positive drop-in centre provides a safe space free of prejudice and harassment, with hot meals and laundry facilities.

Other projects who want to help meet the needs of young people could learn from Positive Youth by listening to what young people are saying, and facilitating their own initiatives - even if this involves taking a few risks. There is scope for the youth service to liaise with local Body Positive groups. Positive Youth have found Kensington and Chelsea very helpful, allowing the use of facilities and providing grants, with Hazel attending youth service staff meetings.

***Positive Youth**, Body Positive, 51b Philbeach Gardens, London SW5 9EB (tel. 071 835 1045). The group can provides speakers to talk to groups of young people, health workers, etc. about living with HIV.*

Barnardos Broad Street Project

The Broad Street Project works with young people with a range of life threatening illnesses, including HIV/AIDS. Its initial work around HIV developed in partnership with the Haemophilia Society, with young people affected by both haemophilia and HIV. Among the issues facing such young people are:

• when and how to communicate with others about their HIV status. For children told of their HIV diagnosis at an early age, HIV is a very important part of their identity as they grow up. They may wish to tell others about it, but may face problems if they do.

• children may not be told that they, or their siblings, are HIV+.

• consent to medical treatment: at the age of 16 young people may experience a sudden change in status, from being told what to do to being expected to make their own decisions. The Project has helped young people to deal with this, as well as helping adults to come to terms with young people making decisions they may not agree with (e.g. refusing treatment).

The Broad Street Project runs a number of services itself, catering for a range of ages (0 - 25). An HIV helpline especially for young people was set up because local HIV education was raising questions that nobody could answer. Young people did not have access to services, particularly in rural areas.

The Project has a group for young people affected or infected by HIV, which includes a small counselling group. They are also have a hospital visiting service to visit young people when they are in hospital or at home and unable to get about, and can provide various types of day to day support to families such as transport and emergency childminding.

In addition to providing its own services, the Project sees its role as being to work with other agencies to help them make their services more accessible to older children. At present services tend to be focused either on very young children or on adults, with little for those in between. For instance GUM services are generally not geared towards under-16s; the Broad Street Project is part of a working group looking at establishing a test counselling service especially for young people.

***Barnardo's Broad Street Project,** 90 Broad Street, Birmingham B15 1AU (tel. 021 633 3522). The freephone HIV helpline number is 0800 317780.*

NEW PUBLICATIONS

▣ **HIV and the under-5s: a guide for workers and carers** (George House Trust, 1993, £6.50).
A completely revised and updated edition of this guide for those working with children under 5, produced by the main voluntary HIV organisation in the North West of England. The 40 page guide includes information, practical tips, and quizzes covering such areas as confidentiality, good practice and hygiene, special needs, and service provision. [George House Trust, PO Box 201, Manchester M60 1PU]

▣ **The gigantic snotty germ dream** (L.I.M. Consortium,1993).
Produced by HIV workers in Islington, Manchester, and Lewisham, this is a full colour educational comic aimed at key stage 2 children (aged 7 -11), tackling the issues of immunity, transmission and HIV. 50p per leaflet (with a 10% reduction for 30 or more). [From: Rosie Dzanjalimodzi, Health Promotion, St Pancras Hospital, 4 St Pancras Way, London NW1 OPE]

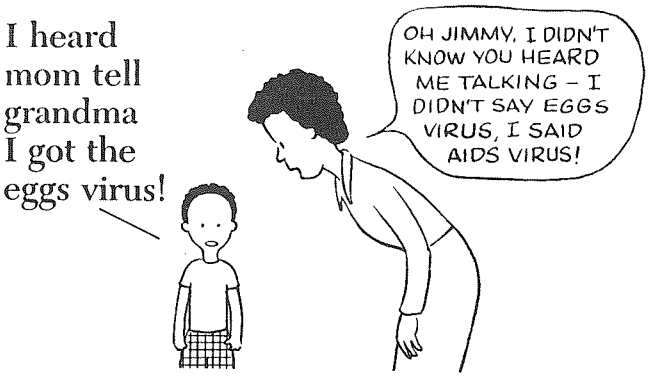
▣ **We're talking about AIDS** - Karen Bryant-Mole (Wayland, 1994, £7.99).
Illustrated with colour photographs, this book is aimed at 9 -14-year-olds. Information is included on the immune system, HIV transmission, condoms, "how does it feel to have HIV?", and other issues. 32 page hardback..

▣ **Housing provision and children affected by HIV infection and AIDS** - Joan Fratter (Barnardo's /Local Government Management Board, 1993).
In this report Joan Fratter (Barnardo's Positive Options) draws on a wide range of examples to demonstrate potential housing problems, and how housing departments can make a positive contribution to to promoting the welfare of children affected by HIV. Among the issues she addresses are families needing rehousing because of harassment, and children being too young to take on a tenancy when their parent dies. [Details from: Les Woods, Local Government Management Board, Arndale House, Arndale Centre, Luton LU1 2TS, tel. 0582 451166, ext.288]

▣ **Guidelines for management of children with HIV infection** - Diana Gibb and Sam Walters (AVERT, 1993, £4.00).
A revised 2nd edition of the booklet written by clinicians from Great Ormond Street and St Mary's hospitals in London, this includes guidelines on symptoms, treatment, and other aspects of management. [AVERT address below]

▣ **A guide to HIV infection and childbearing** - Danielle Mercey, Susan Bewley, and Peter Brocklehurst (AVERT, 1993, £3.00).
The aim of this booklet is to provide information about HIV and childbearing to help clinicians provide optimal care for women with HIV. It covers counselling about HIV and pregnancy, management of HIV positive pregnant women, birth, and follow-up. [AVERT, 11 Denne Parade, Horsham, West Sussex, RH12 1JD, tel. 0403 210202]

▣ **Developing new patterns of family placement for children affected by HIV and AIDS** (National AIDS Trust, 1993, £3.00).
Report of a seminar for foster carers organised by NAT with the Thomas Coram Foundation and Barnardo's Positive Options in September 1993. [Deborah Deoraj, National AIDS Trust, 6th Floor, Eileen House, 80 Newington Causeway, London SE1 6EF, tel. 071 972 2845]


I heard mom tell grandma I got the eggs virus!
OH JIMMY, I DIDN'T KNOW YOU HEARD ME TALKING – I DIDN'T SAY EGGS VIRUS, I SAID AIDS VIRUS!
From: "Jimmy and the Eggs Virus"

US PUBLICATIONS

▣ **A death in the family: orphans of the HIV epidemic** - ed. by Carol Levine, United Hospital Fund of New York, 1993.

Edited by the director of the Orphan Project, this book includes 17 chapters on the growing population of young people surviving a parent's death from AIDS (in the US, an estimated 18,500 children had been left motherless by AIDS by the end of 1991).

As well as describing innovative services that have been developed for such children, a number of personal accounts by family members are included. Mariselle, a 16-year-old describes her experience of living with her parents and sister all of whom have HIV:

"So much of my time is spent worrying about what will happen to them... Being left when both my parents and sister are gone is very, very difficult to consider. Will I be able to go on? Will I still be able to go to college - something I have been dreaming about doing for a long time? Will I be the same person with the same positive attitudes? Will I be able to love again like I love my family now?".

Published by the United Hospital Fund, 55 Fifth Avenue, New York, NY 10003-4392 ($10.00 plus postage and packing).

▣ **The National Pediatric HIV Resource Centre** publish a wide range of publications, including:

Jimmy and the Eggs Virus: a child's viewpoint of what it's like to find out about being infected with HIV ($2.00).

HIV and AIDS in children- questions and answers: intended to be used as an informational resource for the general community as well as an introductory work for professionals ($2.00)

Parent Information Booklets: A set of ten booklets covering such issues as HIV testing and telling a child about HIV ($2.00 a set).

*Order from: **National Pediatric HIV Resource Center**, 15 South Ninth Street, Newark, NJ 07107, USA, fax. (201) 485 2752.*

EVENTS

3 May 1994: **Positive partners/positively children,**, London. Candy Duggan from Great Ormond Street hospital will be discussing her work with families and answering any questions in a session at Positive Place in South East London. Details from Maggie Woonton, 071 738 7333.

11 - 13 May 1994: **Children and families with HIV/AIDS: practice skills**, Birmingham. Organised By LBTC: Training for Care and British Association of Social Workers. Contact: Brenda Pascal 071 388 2041.

16 - 17 May 1994: **Family placement needs of children affected by HIV/AIDS**, London. Details from Joylette Anderson, Thomas Coram Foundation for Children, 071 278 2424. Organised with National AIDS Trust and Barnardo's Positive Options.

24 May 1994: **Respite care for families affected by HIV**, London. National Forum on AIDS and Children meeting (tel. Neil Orr 071 278 9441)

10 June 1994: **Scientific update on HIV in women and children**, Edinburgh. Meeting aimed at clinicians and practitioners interested or involved with children and HIV, organised by Paediatric AIDS Resource Centre, 031 668 4407.

24 June 1994: **Child sexual abuse and HIV/AIDS**, Wakefield. Organised by Wakefield Healthcare and Barnardo's. Details from Val Barker, 0924 814400, ext. 3037.

7 - 10 July 1994: **AIDS Impact- 2nd international conference on biopsychosocial aspects of AIDS and HIV infection**, Brighton. Conference topics include children, and the family. Details from: AIDS Impact Conference Organisers, c/o Dept. of Psychology, St Mary's Hospital, Praed Street, London W2 1NY.

8 July 1994: **Young men and sexual health**, Sheffield. Details from Sheffield Centre for HIV and Sexual Health, 0742 678806.

22 - 23 September 1994: **Child care workers and HIV**, Edinburgh. Organised by PARC, 031 668 4407.

13 October 1994: **Women with HIV and AIDS and their families**, London. Details from Courses Office, RPMS Institute of Obstetrics and Gynaecology, Queen Charlotte's and Chelsea Hospital, Goldhawk Road, London W6 OXG.

1 December 1994: **World AIDS Day: AIDS and the family**. Various events worldwide.

*If you would like to publicise a course or conference in **ChildAIDS**, please send the details to the editor (address on page two).*

NEWCASTLE CONFERENCE

Newcastle Social Services held a two day conference on **HIV/AIDS and children: what's needed?** in March. The conference brought together workers from social services, health services, and the voluntary sector to begin looking at how local services could be developed to meet the emerging needs of children and families affected by HIV.

With a Regional Haemophiliac Reference Centre based at the Royal Victoria Infirmary in Newcastle, there is a wealth of experience locally of working with older children affected by HIV. Two sets of parents whose sons died from AIDS addressed the conference, and Pat Latimer (Social Worker at the Haemophilia Centre) discussed some of the problems children face. HIV related developmental problems can result in children being teased at school because they aren't growing as fast as others. Children sometimes complain of feeling overprotected, of "being wrapped in cotton wool" as one put it. Haemophiliacs infected with HIV as children have grown up and had children of their own, in the process having to come to terms with a range of new anxieties.

Nicola Sugden, Social Worker in the Infectious Diseases Unit at Newcastle General Hospital emphasised that many gay and bisexual men with HIV live in a family network where there are children. In such situations, children may not always be told after the death of a parent about their sexuality, and the sense of being excluded from an unspoken family secret can add to their distress.

Learning from other illnesses

It was also recognised that those confronting AIDS have much to learn from the the experience of children and families facing other serious illnesses. Maureen Hitcham talked about her work with children with cancer and other life threatening conditions, as well as their siblings. She has developed a video and book **Somewhere over the rainbow***, for working with such children. There was also a presentation on the work of the Barnardo's Orchard Project which helps bereaved children in the North East of England.

Newcastle Social Services HIV/AIDS Project are keen to develop policy and practice which acknowledges children's rights. Neil Orr of the National Forum on AIDS and Children was invited to discuss children's rights issues, while Huw Meredith (National AIDS Trust) provided an overview of good practice.

The conference was organised by Jean Lovie, HIV/AIDS Services Development Officer, HIV/AIDS Project, Civic Centre, Newcastle upon Tyne NE1 8PA (tel. 091 232 8520).

**Details from Maureen Hitcham, Paediatric Oncology Social Worker, Royal Victoria Infirmary, Queen Victoria Road, Newcastle NE1 1HL.*